439 The expert CF patient; an untapped resource

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The term "expert patient" Is synonymous with those who suffer from a chronic illness such as CF. Current initiatives suggest that they are untapped resource in the management and evaluation of chronic illness and in health care education. This paper aims to explore the nature of expertise in people with cf and their carers and examine the implications of being an expert patient or carer for themselves, health care providers and educationalists.

Method: 17 interviews were carried out with 6 families over a one year period. Data was analysed using thematic analysis.

Results: *Theme 1*: Young people as experts of their condition.

- Use of sophisticated and medicalised language when discussing their condition
- Expertise is embedded into daily routines and becomes taken for granted.
- Self-treatment regimes are increasingly technical and formerly the domain of skilled health care professionals.
- Expertise is grounded in "living in the moment" and does not include the whole illness trajectory.

Theme 2: Parents as experts.

- Parents regarded as experts at home but role is relinquished when children are hospitalised.
- Parents increasingly undertake technical roles which increases the burden of care.
- Parent's knowledge of the child and their disease allows them to detect subtle changes in condition and take action accordingly.

Discussion: Expertise is present in patients with CF and their carers but can be defined differently in accordance with the literature [1]. Informal expertise is associated with less power and status than formal expertise. Health Care professionals and educationalists must consider how these differences in expertise can be utilised to maximise patients' and carers' journeys and students' learning experiences.

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Reference(s)

[1] DoH. The expert patient: a new approach to chronic disease management in the 21st century. 2001; London: HMSO.

440 Gene therapy (GT); what adults with CF really think. A multi-centred study

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People with CF have been anticipating the arrival of viable GT for almost two decades, resulting in the benefits being perceived by some, as exaggerated [1], leading to disillusionment and frustration [2,3]. Yet with one exception [4], there has been no empirical attempt to explore knowledge and views among adults with CF. Adults with CF (N = 281), from 4 regional CF units completed a clinic-based questionnaire [4].

13% of participants had never heard of GT, 64% believed the effect of GT to be prevention of further lung damage, with 26% believing GT will slow down future lung damage. Although 78% of participants had not sought information about GT, 76% did not feel they had the right amount of information and would like to know more. Participants stated that they would like to know how GT might work and whether or not they would benefit from it, (75% and 74% respectively). Professionals directly associated with CF were seen as the ones who should provide information. The CF team was seen as being the most important provider of information (79%) and the majority believed that information should be provided regularly as standard 48%), in the form of an information leaflet (48%).

These results highlight the desire among patients for a different, more local, way of receiving information about GT regularly. Discussion focuses on the practical implications for psychoeducation and clinical practice.

Reference(s)

[1] Orkin & Motulsky, 1995.
[2] Leiden, 1999.
[3] Friedmann, 2005.
[4] Thomas et al., 2007.

441 The psychosocial impact of a late CF diagnosis

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Introduction: There is a paucity of research into the psychosocial impact of late diagnosis in CF adults. This study aimed to explore:

1. Pre-diagnosis experience, concerns, expectations and disease knowledge
2. Feelings about diagnosis delivery and information supplied
3. Post-diagnosis adjustment, information sought, belief changes, social support and improving the process

Methods: Semi-structured interviews were conducted with 10 CF patients diagnosed as adults in the last 10 yrs. Analysis was based on interpretative phenomenological analysis.

Results: Topics raised by participants included diagnosis process, information needs and psychosocial support, social adaptations, comparison to others and past self, loss, identity, emotional impact and coping. Frustration with past medical contact and time to diagnosis a key theme; though once diagnosed many felt the consultation well delivered and a relief. At diagnosis participants felt overwhelmed by information often focusing on negative aspects of CF rather than empowering them.7 participants felt a need for psychosocial input including finance and employment information and counselling. Public perceptions of CF as a 'child disease' gave a feeling of isolation and social support sometimes lacking in some family members who distanced themselves from genetic implications of CF or feeling guilty. Infertility issues were also considered important.

In comparing 'their own' to 'child onset' CF however participants appraised themselves as lucky.

Conclusion: Late CF diagnosis requires carefully tailored information, psychosocial support and close follow up to enable adaptation and acceptance of diagnosis. Issues such as fertility, employment and financial support may be particularly important.

442 Coping with cystic fibrosis – CF adults and parents of a child with CF in Czech Republic

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Aims: This study aimed to (a) describe the ways of coping employed by adults with CF and the parents of a child with CF (b) to compare the coping strategies of these groups and (c) to evaluate coping strategies in terms of age and gender.

Methods: The research was performed with 104 individuals from the Czech Republic: 41 adults with CF (mean age 24.41 years) and 63 parents (mean age 40.92 years). Participants completed the Cystic Fibrosis Coping Scale which measures four ways of coping: optimistic acceptance, hopefulness, distraction, and avoidance.

Results: Optimistic acceptance was the most frequently used coping strategy for both adults with CF (mean score 65.24), and parents of a CF child (mean score 64.48). This was followed by hopefulness (CF adults mean score 45.71; parents mean score 44.92), distraction (CF adults mean score 41.8; parents mean score 35.48), and least of all, avoidance (CF adults mean score 34.90; parents mean score 19.06). Adults with CF employed distraction and avoidance coping significantly more than parents. Within both groups there were trends to indicate that men use distraction and avoidance coping more frequently than women. Younger parents (<39 years) were more hopeful than older parents (>40 years), although there were no differences in coping behaviors between parents of a younger (<18 years) or older (>18 years) child.

Conclusions: Adults with CF and parents of a CF child engage in a range of coping behaviors. It is encouraging that optimistic, determined and problem focused strategies make up the dominant way of coping for both groups.